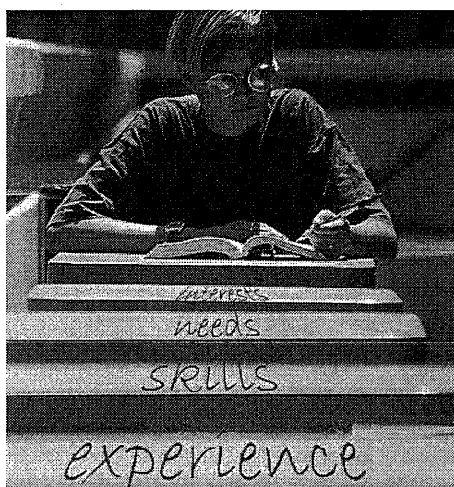


Preparing for the future

A checklist for parents

With their attention focused on providing for their child's immediate needs, many families have been startled to discover something has been missed in preparing for their child's transition to adulthood. A number of guidebooks and other tools are available to help teens and young adults through stages of transition, but parents also need guidance to be effective in their many roles including caretaker, financial provider, and educator.

Quite a few families of children with disabilities have found a surprise or two in the various systems and processes their child encounters as he or she proceeds through transition. Some families have reported finding out too late about services or deadlines for application, or being taken unaware that they no longer are legally entitled



to obtain information or to make decisions regarding their child's medical care. Others may never become aware of benefits or resources for which their child could be eligible.

"Teaching advocacy skills is huge," said Leanne Murillo, Youth Transition Coordinator at Arizona Bridge to Independent Living. "When young people turn 18 and go to the doctor or proceed into college or enter the job market, the decisions become theirs, not their parents. It is critical to help parents understand how essential it is to train their child to advocate for themselves and then to let go and let that child do it on their own."

Families need open, honest discussion about options. The best

defense against the unexpected is discarding assumptions and becoming educated. Seek out information from multiple sources and ask for clarification of anything that is not clear to you. Educate your child by including them as much as possible in decisions and processes that affect their future.

This issue highlights important milestones, services, benefits, procedures and more that families have experienced as areas of concern.

— continued on page 3

"So often when I talk to parents about transition issues, their eyes just gloss over and they say 'I would have never thought of that!'"

Debbie Weidinger, Co-founder and President of AZ ASSIST, a support group for parents and their teens or young adult children with autism spectrum diagnoses.

azassist.com

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From the Director...

As I sat down to write this, I had just completed a journey of 1500 miles driving a moving van and hauling a piano. One hour into the journey, feeling good about being on our way, we were forced to pull off the road and wait for assistance to change a damaged tire.

There were "blind spots" — times when we just couldn't see very well and had to be exceptionally cautious. The truck was buffeted by strong winds, and at one location the roadway was closed because of wind and dust conditions, adding another day to our trip.

Driving was tiring, seats were uncomfortable, and we changed drivers often to keep from wearing out. Keeping the fuel tank full was expensive.

At the end of the trip, we were tremendously relieved and ready to celebrate. The piano, our precious cargo arrived safe and in good condition. It was ready to be an instrument for its intended purpose, enriching our family life with its music.

This metaphor of setting out on a long trip, facing the unexpected, experiencing disruptions and delays, needing support, and not always being sure you're seeing everything clearly, might be one way to describe the journey taken by parents of children with disabilities. We navigate through some difficult times and carry our hopes and dreams for reaching the right destination.

Have a safe and enjoyable summer, and take heart in knowing there are many of us out there on the same road.



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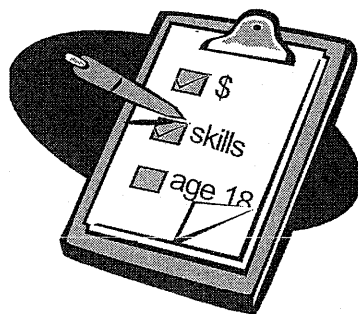
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Parent to Parent support is the heart of Raising Special Kids. Information about local services, educational programs, advocacy, or special health care needs is available in both Spanish and English. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)3 non-profit organization.

Planning for the future

Financial Planning

- ☐ Families should be aware of how their child's ownership of assets could affect eligibility for benefits from social security, Medicaid (AHCCCS in Arizona), and other services. Identify how financial support your child may receive impacts other benefits.
- ☐ Consult with a legal professional who specializes in estate planning for families of children with special needs. Ask about special needs trusts, education savings plans, wills, and life insurance.
- ☐ Learn about Social Security – Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), community services for adults with disabilities, Social Security Administration work incentives: PASS, Ticket to Work, 1619a and b.



- ☐ What services will your child need to re-apply for at age 18?

18 - The Age of Majority

- ☐ When a child turns 18, under law, their rights and responsibilities change regardless of the presence of a disability. Consider options well in advance if there is a need for someone to act in a decision making capacity for your child after they turn 18.
- ☐ *Before your child turns 18, learn about guardianship (various types), conservatorship, power of attorney, and other options. This information is addressed in Raising Special Kids' Guardianship and Other Legal Options Workshop.*
- ☐ At age 18, students receive a Transfer of Rights notice from school—at this point parents no longer have the right to the child's records unless their child signs a release.
- ☐ An Individual Education Program (IEP) ends when a student exits high school, it does not extend into post secondary education (such as college or trade school.)
- ☐ All males must register for Selective Service (regardless of disability or special health needs.)
- ☐ Transfer to adult health care – Most children will be required to transfer out of a pediatrician's care. Many more children with severe disabilities or chronic health problems are now surviving into adulthood, and a lack of qualified adult health providers may, in some cases, necessitate retaining care from a pediatrician. Not all pediatricians or pediatric specialists will allow a child over 18 to continue to be treated in their practice. Pediatric physicians should have a transition plan in place for their patients who have disabilities or special health care needs.

A Job and/or Secondary Education

- ☐ Identify the child's strengths, interests, and needs.
- ☐ Is post secondary education a goal? Consider the options (university, community college, vocational training, personal development classes, or other options.) Contact the preferred school at least two years ahead for information on admission requirements and the availability of disability services.
- ☐ Is a job after graduation a goal? Vocational assessment should be done in high school. Contact Vocational Rehabilitation Service (they may become involved in the IEP process); learn about One-Stop Career Centers and other employment assistance for people with disabilities.
- ☐ Incorporate college preparation or vocational training into IEP transition planning.
- ☐ Assemble documentation of disability with most recent evaluation results.
- ☐ Explore financial aid resources.
- ☐ Be aware that at the college level parents need written consent from the student to obtain access to the student's records.
- ☐ Know the difference between the laws that govern education at the secondary level (IDEA) and at the college level (ADA).
- ☐ 504 plans may follow an individual into college or the workplace.
- ☐ Help your student find opportunities to gain experience through work or volunteer activities.

Planning for the future

Housing

- ☐ Learn about possibilities for independent living.
- ☐ Consider various housing options e.g.: living by oneself, finding a roommate, entering a group home, or staying with family.
- ☐ Research types of group homes in the area the child wants to live in, or consider beginning a co-op with other families.
- ☐ Examine funding options.
- ☐ Learn about housing rights (Fair Housing Act).

Daily Living Skills

Identify areas of need and means for acquiring needed skills in:

- ☐ Transportation
- ☐ Managing finances
- ☐ Maintaining a household (cooking, shopping, laundry, keeping house)



- ☐ Social, communication, and self advocacy skills
- ☐ Self knowledge regarding disability, health and medications, sexuality, available support network
- ☐ Obtaining health care, dealing with insurance. Creating a medical journal can be useful; include lists of providers, medications, instructions for Durable Medical Equipment upkeep and repair and general health history.
- ☐ Recreation and leisure options
- ☐ Planning for emergencies

Resources:

- http://www.dol.gov/odep/documents/creating_path_to_Employment.pdf
- http://www.dol.gov/odep/documents/essential_job_skills.pdf
- <http://www.medicalhomeportal.org/living-with-child>
- <http://www.nsttac.org/> • www.hrtw.org • www.ncset.org

Other

- ☐ Obtain a drivers license or state ID
- ☐ Register to vote

Developmental checklist for health behaviors

Adapted from checklist developed by Kentucky Commission Children Special Health Care Needs

- Is building understanding of condition/special needs and treatments
- Can describe condition to others
- Can determine when condition is worsening
- Is active/exercises to maintain physical fitness
- Knows basics of nutrition
- Has someone to talk to about concerns
- Working with parents/caregivers in doing self-care related to meds and treatments
- Has plan for emergencies
- Carries list of medications, list of health care providers
- Carries copy of insurance/medical card & summary medical information
- Answers questions from medical providers about condition
- Knows how condition and treatment affects physical, mental, sexual development
- Knows how smoking, drinking, chewing, drugs affect body and condition
- Understands sexuality, pregnancy, and birth control
- Sees doctor for some time privately
- Manages own medication and treatment regime; notifies caregiver of need for med refills
- Knows what equipment does and how to fix minor problems
- Knows side effects of medication and interactions with food, alcohol, etc.
- Family explores guardianship if needed (age 18 is age of majority when youth legally makes own decisions); assent to consent; health surrogate
- Has plans for adult health care providers (primary, specialty, dental, DME, pharmacy, therapy, mental health)
- Has plans for adult health insurance
- Knows how to use health insurance/medical card
- Has adult health care providers
- Has signed release to transfer records
- Has copy of own records



Special Education Forum FREE for Parents

Presented by Attorneys Who Practice Special Education Law

Saturday, August 7th, 2010

8:00 a.m. to 12:00 noon

Disability Empowerment Center

The Nina Mason Pulliam Conference Center

5025 E. Washington St., Phoenix, AZ 85034

Topics covered will be:

- Child Find
- Evaluations
- Eligibility
- IEPs (Individual Education Plans)
- Procedural Safeguards
- FBA (Functional Behavior Assessment)
- BIP (Behavior Intervention Plan)
- Short-term suspensions and other consequences
- Long-term suspension and expulsions
- Procedural Safeguards
- Panel of experienced parents who've "been there" will share their experiences

Refreshments will be provided. No child care available.

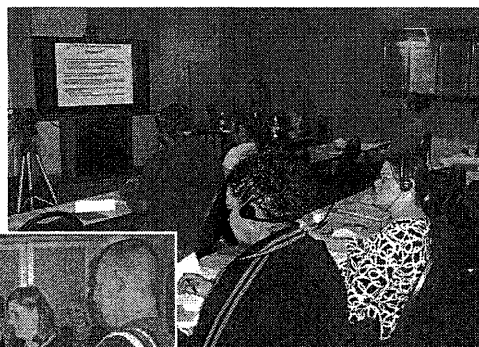
Space is limited, please register by contacting Raising Special Kids at 602-242-4366.

Therapies Conference

Raising Special Kids' conference on therapies in May, the first of a series of parent trainings funded by a grant from Virginia G. Piper Charitable Trust, was a tremendous hit with parents.

80 attendees learned hands on techniques that can be implemented at home to help their children.

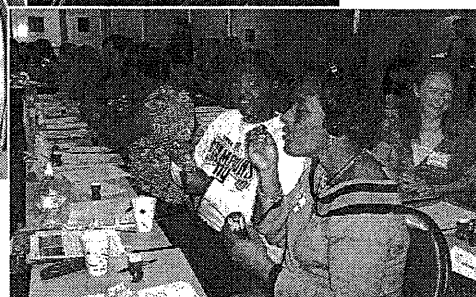
"Thank you!! For a wonderful conference today!! I learned so much and got a lot of resources that I did not have before!"



Live translation was available for Spanish speaking families.



Attendees had opportunities for one-on-one questions with therapists and presenters.



Raising Special Kids gratefully acknowledges our generous donors of goods and services:

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Wist

Raising Special Kids Calendar

Call 602-242-4366 or 800-237-3007 to register

Our office location is a fragrance-free environment, please avoid wearing fragrances.
Disability Empowerment Center, 5025 E. Washington St., #204, Phoenix, AZ 85034

Positive Behavior Support

Training on effective techniques for behavior management.

Sat. 6/26/10, 12:30 – 2:00 p.m.

Wed. 7/14/10, 6:00 – 7:30 p.m.

Wed. 8/18/10, 6:00 – 7:30 p.m.

(Catholic Charities)

Sat. 8/21/10, 10:00 – 11:30 a.m.

(Highlands Church, Scottsdale)

Wed. 9/15/10, 6:00 – 7:30 p.m.

Resilient Relationships

Create and maintain a healthy couples relationship through the journey of raising a child with special needs.

Fri. 9/17/10, 1:30 – 3:00 p.m.

Can you hear me now?

Techniques for effective advocacy. What to ask, how to ask it.

Wed. 6/16/10, 6:00 – 7:30 p.m.

(Highlands Church, Scottsdale)

Sat. 7/17/10, 8:30 – 10:00 a.m.

Wed. 8/4/10, 6:00 – 7:30 p.m.

Sat. 9/25/10, 10:00 – 11:30 a.m.

Guardianship Workshop

Learn about what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.

Sat. 6/26/10, 2:30 – 4:00 p.m.

Tue. 7/20/10, 6:30 – 8:30 p.m.

Sat. 8/21/10, 2:00 – 4:00 p.m.

Thu. 9/16/10, 10:00 – 12:00 p.m.

IEP Basics

Learn about the purpose of IEP's through an overview of the document and meeting.

Sat. 6/26/10, 8:30 – 10:00 a.m.

Thu. 7/8/10, 6:00 – 8:00 p.m.

(Lodestar, Phoenix)

Thu. 7/15/10, 10:00 – 12:00 p.m.

Thu. 9/30/10, 10:00 – 12:00 p.m.

Advanced IEP Training

Learn about the requirements for IEP's and how to actively participate in team meetings.

(Recommended: first attend *Understanding the IEP.*)

Thu. 9/9/10, 10:00 – 12:00 p.m.

Understanding 504

Learn about the intent and requirements of Section 504, responsibilities of schools, and samples of 504 accommodations.

Tue. 7/27/10, 1:30 – 3:00 p.m.

AzEIP to Preschool Transition

Learn about the requirements for transition and tips for a smoother process.

Sat. 7/17/10, 10:00 – 11:30 a.m.

Wed. 8/11/10, 10:00 – 12:00 p.m.

Sat. 9/25/10, 12:00 – 2:00 p.m.

High School Transition

Learn how to prepare youth for transition from high school to higher education, employment, and life in the community.

Wed. 8/4/10, 4:00 – 6:00 p.m.

Bully-Free Environments

Learn how to recognize bullying, effectively Respond, and build positive solutions.

Mon. 6/14/10, 6:00 – 8:00 p.m.

(Lodestar, Phoenix)

Sat. 6/26/10, 10:30 – 12:00 p.m.

Wed. 8/18/10, 7:30 – 9:00 p.m.

(Catholic Charities, Phoenix)

Wed. 9/15/10, 4:00 – 6:00 p.m.

Parent/Professional Collaboration

Learn ways for parents and professionals to develop working relationships.

Wed. 8/25/10, 10:00 – 12:00 p.m.

Notice our

ALTERNATE LOCATIONS

(workshops listed in red at left)

Highlands Church

9050 E. Pinnacle Peak Rd.
Scottsdale, AZ 85255

Catholic Charities/Arizona Partnership for Children

4747 N. 7th Ave.
Phoenix, AZ 85013

Lodestar Family

Connections Center

2320 N. 20th St.
Phoenix, AZ 85006

Evaluations & Assessments

Learn about the types of tests and what they measure, scoring results and what the bell curve means in formal assessments.

Wed. 9/29/10, 10:00 – 12:00 p.m.

Volunteer Training

Your skills count! Become a parent volunteer for Raising Special Kids and share what you've learned as a parent of a child with special needs.

Thu. 6/10/10, 10:00 – 12:00 p.m.

Mon. 7/26/10, 6:00 – 8:00 p.m.

Sat. 9/4/10, 10:00 – 12:00 p.m.

IEP 1-to-1 Consultation

Bring your child's current IEP as well as your questions and concerns. We will privately address your individual issues and offer solutions and strategies to help you advocate more effectively for your child.

Call for an appointment:

602-242-4366 or 800-237-3007.

www.raisingpecialkids.org